CHAPTER 1

Ecosocial and Environmental Justice Perspectives on Breast Cancer: Responding to Capitalism's Ill Effects

Mary K. Anglin

> With nearly 80,000 chemicals on the market in the United States, many of which are used by millions of Americans in their daily lives and are un- or understudied and largely unregulated, exposure to potential environmental carcinogens is widespread. One such ubiquitous chemical, bisphenol A (BPA), is still found in many consumer products and remains unregulated in the United States, despite the growing link between BPA and several diseases, including various cancers.
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> LaSalle D. Leffall, Jr. and Margaret L. Kripke, Preface to *Reducing Environmental Cancer Risk*

In a manner evocative of Rachel Carson's *Silent Spring* (1962), Leffall and Kripke (2010) recently called attention to the massive number of synthetic chemicals circulating throughout the United States, as well as globally, and whose impact on human health and the environment remain largely unknown. While the American Cancer Society criticized the report for being "provocative" and representing "hypothesis" as "consensus" (Sampson 2010), it was based on

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the limited scientific evidence available – and this was precisely the concern identified by Leffall and Kripke. Among other things, their analysis raised the questions: Why has so little cancer research focused on the interaction of environmental factors with human physiology, and what is known or knowable at this juncture? Is it possible to talk meaningfully about breast cancer "prevention" in the absence of such information? One might add: Which interests are served when the proprietary claims of industry outweigh the public's right to know about the various effects of the familiar and not-so-familiar chemicals dispersed throughout our world? Whose voices are authoritative; which are left out of official discussions; and where is there room for popular dissent? And what does any of this mean for an understanding of the links between health and environmental conditions, much of which have been altered by human commerce in its regional and global forms?

With breast cancer as its focus, this chapter provides an account of a controversy in medicine – and its gendered and racialized terms – as well as an exploration of how forms of activism and shifts in paradigms about cancer have opened up new avenues for investigating social and environmental parameters of illness and health. In conjunction with ecosocial approaches articulated by public health researchers, the present analysis draws upon anthropological views concerning the relationship between political economy, health, and the environment, and the use of ethnographic methods to document their interplay through the spaces of daily life. Central to such a discussion has been the development of an anthropology of cancer, with attention to breast cancer specifically, and to which Leo Chavez, Holly Mathews, Juliet McMullin, Diane Weiner, Maren Klawiter, and others have contributed (Klawiter 2008; McMullin and Weiner 2008; Mathews, Burke, and Kampriani 2015). Finally, I draw upon my own ethnographic work in northern California (1992–) on breast cancer, activism, and racial/ethnic inequalities, in conjunction with writings and testimony by and about women living with cancer.

As Rachel Carson argued more than 50 years ago, the pivotal issue is whether and how such knowledge might be employed to reconfigure environmental and related policies for the United States, as well as elsewhere in the global North:

> The choice, after all, is ours to make. If, having endured much, we have at last asserted our "right to know," and if, knowing, we have concluded that we are being asked to take senseless and frightening risks, then we should no longer accept the counsel of those who tell us that we must fill our world with poisonous chemicals; we should look about and see what other course is open to us. (Carson 1962: 277–278)

When *Silent Spring* was first published, Carson did not disclose her own diagnosis of advanced breast cancer, lest the conclusions of long-term scientific research appear to be limited by personal bias. However, breast cancer activists and others articulating the need for environmental justice draw upon both dimensions of Carson's life and work to address matters of equity, health, and sustainability on multiple fronts.

Environmental organizations have for some time argued that the approach of government agencies in the United States is to be "inconclusive by design" in investigating potential hazards associated with synthetic chemicals, and non-interventionist about their production, distribution, or usage (Russell, Lewis, and Keating 1992). Passage of the US Toxics Substances Control Act (TSCA) in 1976 mandated the registration of chemical compounds prior to their widespread manufacture or importation; by 2006, over 82,000 chemicals had been registered through the TSCA Inventory (Environmental Protection Agency/EPA 2007). However, the 1000–1500 applications received each year from prospective manufacturers include "little or no toxicity or fate data" about the compounds themselves, since this is not a formal requirement (EPA 2007: 4). Furthermore, synthetic chemicals existing prior to 1976 were automatically included as part of the TSCA Inventory.[1] To cite a review conducted on behalf of the nonprofit organization, the Breast Cancer Fund, "Complete toxicological screening data are available for just 7 percent of these chemicals and more than 90 percent have never been tested for their effects on human health" (Gray 2010: 14).

In the aftermath of TSCA's passage, regulatory agencies have continued to prioritize economic considerations, with "scientific certainty" about harm as "the only justification for advocating active protective policy measures" (Silverstein 2012: 1; see also Brown 2011; Clapp 2012). Additionally, some manufacturing interests have demonstrated their willingness to forcefully dispute and/or restrict access to scientific data on the toxicities associated with particular compounds (Michaels 2008; Morris and Hamby 2013; Aviv 2014). As a result, the continued viability of chemicals such as bisphenol A (BPA) is not regarded as surprising, despite evidence of health effects and a presumptive link to cancer (National Toxicology Program 2008).

What distinguished the commentary by Leffall and Kripke, then, was not the originality of their argument or muckraking tone. Rather, it was the status of being the *2008–2009 Annual Report from the President's Cancer Panel*, the advisory board established in 1971 to monitor cancer policy and provide guidance to the President of the United States. Reasoning that "the grievous harm from this group of carcinogens has not been adequately addressed by the National Cancer Program," Leffall and Kripke (2010) ended their prefatory letter to President Barack Obama with an appeal for radical change:

> The American people – even before they are born – are bombarded continually with myriad combinations of these dangerous exposures. The Panel urges you most strongly to use the power of your office to remove the carcinogens and other toxins from our food, water, and air that needlessly increase health care costs, cripple our Nation's productivity, and devastate American lives.

Cancer prevention, they argued, requires more than biomedicine's current "narrow focus" on individual decision making and behavior as the principal source of disease risk (Leffler and Kripke 2010: vii). Greater emphasis must be placed on protecting human health and the ecosphere from unwarranted, often unidentified exposures to harmful substances – with the burden of proof shifted

toward determining the *safety* of chemical compounds and with much stricter regulation.[2] In short, expert testimony before the 2008–2009 President's Cancer Panel and the Panel's own conclusions recorded the need for "a comprehensive, cohesive policy agenda" reflecting the precautionary principle.[3]

The Panel's report has been described as "a fundamental shift toward a winning strategy" in the "war on cancer," a much-needed "call to action," "an integrated and comprehensive critique," and, conversely, "unbalanced" for the lesser attention given "modifiable risk factors" at the level of individual behavior (Rizzo 2010; Clapp cited in Cone 2010; Schettler cited in Cone 2010; Thun cited in Sampson 2010; Cooney 2010). For the purposes of the present essay, the *2008–2009 Annual Report from the President's Cancer Panel* represents a watershed moment in a decades-old debate over the role of environmental factors in the etiology of chronic diseases, with cancer as the preeminent example. Of particular interest are the various entities and resources that helped to shape its findings. These include the history and different forms of breast cancer advocacy, the efforts of environmental justice advocates, the collaborative activities of lay or citizen science, decades of public health and clinical studies on breast cancer etiology, ongoing research on the health effects of environmental contaminants, development of international law concerning the precautionary principle, and passage of "green" municipal and state ordinances within the United States.

Beyond Pink Ribbon Marketing: Rethinking the Models of Breast Cancer

One in eight: for women living in twenty-first-century United States, these are the odds of being diagnosed with breast cancer over the course of a lifetime (SEER 2014). During the late twentieth century, the likelihood of a breast cancer diagnosis increased sharply – with breast cancer incidence rising from 101.92 (per 100,000) in 1976, to 141.47 in 1999, and declining slightly to 126.02 in 2010 (Howlader *et al.* 2013). Thus, despite President Nixon's signing of the National Cancer Act in 1971 and proclamation of a "war on cancer," the incidence of invasive breast cancer rose by 36 percent between 1973 and 2000 (Howe and Clapp 2012: 131, 134). In the early 1990s, recognition of that trend inspired a social movement to address the rising rates of mortality from the disease, and the limited diagnostic and treatment options then available.

To quote the web site for Silent Spring Institute, a nonprofit research organization drawing its inspiration from Rachel Carson, "women today are more likely to develop breast cancer than any previous generation" (Silent Spring Institute 2014a). According to estimates in December 2012, 2.9 million women in the United States were living and contending with invasive breast cancer, at all stages of disease, and with some women in remission from cancer. An additional 232,340 women received new diagnoses of invasive breast cancer during 2013, and 39,620 women died from this disease (American Cancer Society 2013; SEER/Surveillance Epidemiology, and End Results 2014). Irrespective

of media coverage of October as "Breast Cancer Awareness Month" in the United States and the promotion of what has been termed "pink ribbon culture," breast cancer remains a significant public health problem and contributor to mortality (Ehrenreich 2001; King 2006; Brenner 2007; Sulik 2011; Howe and Clapp 2012; Anglin 2013). As Ruthann Rudel and colleagues report, "the global economic costs of premature death and disability from breast cancer" are estimated to be $88 billion annually, with the costs of treatment reaching $17 billion per year in the United States alone (Rudel *et al.* 2014: 3; see also ACS 2010; IBCERCC 2013).

Grass-roots organizations in the United States have, for more than two decades, pursued various means to delineate the human costs of this disease. Linda Reyes, cofounder of one such organization, described the growth of a social movement from women's participation in cancer support groups to the initiation of national conversations for which the narratives, histories, and demands of women with breast cancer have a central role: "All that most people with cancer have to count on is each other. That's why it will be people with cancer who take the leadership in challenging the cancer establishment by dragging cancer out into the open as a social and political issue" (1991: 245).

One example comes from testimony given at the 1995 public hearing on "Women, Health and the Environment," before a panel composed of representatives from the EPA, the Food and Drug Administration (FDA), the federal cancer registry (SEER), the American Cancer Society, the California State Legislature, city/county departments of health, the Indigenous People's Network, and the Human Rights Commission. The panel likewise included the Honorable Bella Abzug of the Women's Environmental and Development Organization (WEDO) and representatives from Greenpeace, as sponsors/coordinators of the event and a series of related conferences nationwide. At this hearing, convened in San Francisco, the first speaker translated rates of cancer incidence and mortality into the losses occurring like clockwork to families throughout the country:

> You've heard the numbers. Every three minutes somewhere in the United States a woman is diagnosed with breast cancer and every twelve minutes a woman dies from breast cancer. That's five women every hour, 120 women every day across the U.S. What does that mean in human terms …? It means that we're losing our mothers, our sisters, our daughters, our friends. (Testimony #1, Women, Health and the Environment 1995)

"The numbers" themselves were regarded as indisputable; the primary point of contention was whether they indicated biomedicine's successes or the failure to recognize a health crisis with far-reaching consequences. For similar reasons, a coalition established on Long Island in 1990 took the eponymous, if quickly outdated, name of *1 in 9* (One in Nine 2014) to denote their firsthand knowledge of the breast cancer epidemic and the mission of an advocacy organization that even now continues to operate from the grass roots.

In one sense, it was the apparent simplicity of health statistics, as well as their application in a dominant explanatory framework, which the membership of

regional coalitions and nationally focused advocacy organizations sought to destabilize. Life stories and accounts of health practices illustrate the range of experience which did not neatly correspond with prevailing interpretations of risk and/or prevention: examples of how diagnostic technologies, at times, produced ambiguous or even misleading results; and the many instances in which biotech modalities have fallen short in the treatment of advanced or aggressive cancer (reversing the conventional logic which assigns such failings to cancer patients themselves). As Reyes (1991: 245) noted, "Other people rarely see how defenseless cancer patients are, especially those who are very sick." Activism brought those accounts and experiences to the forefront.

From the outset, grass-roots organizations and women dealing with cancer questioned biomedical accounts that attribute the rise in breast cancer cases to the efficacy of population-based cancer screening. Equally significant have been the limitations of mid- and late-twentieth-century theories regarding breast cancer etiology, and the continued emphasis on "traditional risk factors" for the disease. Listed as traditional or established risks for breast cancer are factors such as a woman's chronological age, family history of breast cancer, benign breast disease, age at menarche, maternal age at birth of first child, nulliparity or childlessness, age at menopause, genetic influence (with the recently discovered breast cancer genes, BRCA 1 and BRCA 2, as preeminent examples), ethnicity, race, and socioeconomic status (Kelsey and Berkowitz 1988; Kelsey and Gammon 1990; Newman, Millikan, and King 1997). The list of "possible," or likely, risks for breast cancer includes obesity (as measured by body mass index), diet and physical exercise, consumption of alcohol, use of oral contraceptives and, more recently, also hormone replacement therapy (HRT).[4]

In short, epidemiologic research has concentrated on family/personal histories of breast and ovarian cancer and benign breast disease; forms of genetic inheritance that are considered significant, if relatively rare (present in 7–10% of diagnosed cases); women's reproductive health strategies, viewed as lifestyle considerations; other behaviors which are understood to be "modifiable"; and parameters of social stratification. Central to the biomedical argument has been the notion that endogenous (or internally produced) estrogens play a crucial role in the development of invasive breast cancer. Childbearing, along with other forms of reproductive decision making, influences a woman's exposure to estrogens and thereby amplifies risk. Insofar as they are comprised of *exogenous* estrogens, oral contraceptives and HRT would likewise elevate breast cancer risk; such effects are seen as magnified by the addition of progestin (Writing Group for the Women's Health Initiative 2002).

From the standpoint of women diagnosed with breast cancer and others involved in advocacy, one of the biggest concerns with the risk factors approach has been the almost exclusive attention to individual-level characteristics. To quote Dianne Dillon-Ridgley, keynote presenter for the Raleigh, NC conference on "Cancer and the Environment" (1995), the line of reasoning can be summarized as "whatever has caused [breast cancer], you did it." Situated within this nexus of multiple and ambiguously defined etiologic factors is "a particular violence of neglect and indifference," as the eco- and cancer activist

Adele Friedman observed in a posthumously published essay (1991: 52). In apparently reprimanding cancer patients for ways of living adopted in the United States over the course of the twentieth century, the risk factors approach, in Friedman's words (1991: 52), echoes "our national disregard for women's lives."

Added to the critiques of biomedical individualism and disregard for women is the point that roughly 70 percent of breast cancer cases in the US do *not* correlate with the list of "established" risks, undermining their explanatory value beyond quite specific instances (Kelsey and Berkowitz 1988; Kelsey and Gammon 1990; ACS 2014). Indeed, for more than 20 years, clinicians/researchers such as Samuel Hellman (1993) have warned against reliance on the risk factors paradigm in the face of contradictory evidence, characterizing this as a form of "dogma."

Virginia Lewiston, a participant in the initial ethnographic interviews I conducted (1991–1994) and thereafter, commented that it was impossible to "make sense" of her own breast cancer diagnosis by "looking inward," so as to locate the causal forces through her life history and/or strategies for raising a family:

> I had been a political activist for more than ten years and had enough of a political perspective to know that it didn't make sense for me to have breast cancer. There was nothing that made sense for me to have it. Therefore it wasn't a question I could answer by looking inward, the "why question." I had to look outward …
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> [I shouldn't have had the disease] for all the reasons that 80% [*sic*] of the women diagnosed with breast cancer shouldn't have had it. It was not in my family. I had done all the right things. I had kids at the right age; I had nursed kids at the right age for the right length of time. Being an academic household, there was enough money for a good diet and enough understanding of the food groups and stuff like that. There was just *no* reason of any of the acknowledged risk factors. They weren't there. Therefore, I shouldn't have had the disease, *but I did*. (Anglin, Interview 0–14, emphasis in original).

Lewiston relied upon an explicitly feminist perspective to examine the logic of the predominant model and to dismiss, on empirical as well as political grounds, its gendered assumptions. At the same time, she recognized the class privileges associated with being part of "an academic household," affecting both her ability to "do all the right things" as well as her health before and after the cancer diagnosis.

Following Lewiston, Dillon-Ridgley, and others, one might argue that if traditional risk factors have not readily explained the cases of middle-class, "White non-Hispanic" women over the age of 50 – the demographic group in the United States for which the rate of breast cancer incidence remains highest (ACS 2013) – still less would this framework account for the experiences of women who are neither Euro-American nor elite. Within the realm of public health research, Krieger, Chen, and Waterman (2010: S132) reported on racial/ethnic differences for the recent (post-1999) and modest decline in breast cancer incidence attributed to decreasing HRT use. As those authors explained,

given the fact of unequal access to high-tech medicine in the United States, HRT was rarely a treatment option and thus would not constitute a risk factor for women from African American, Hispanic, Asian/Pacific Islander, Native American/Alaska Native, and low-income populations.

Likewise, McKenzie and Jeffrys (2009) concluded from their meta-analysis of clinical studies and epidemiologic research that "lifestyle"-related factors and "socioeconomic position" jointly contribute to racial/ethnic disparities in breast cancer mortality, albeit in ways that had yet to be ascertained.[5] Exploring the foundation of these inequalities would require an intersectional approach attuned to multiple facets of social location, as Harold Freeman (2014) noted in his recent commentary for the *New York Times*. From the vantage point of a cancer surgeon who had spent much of his career working in Harlem and the former director of the National Cancer Institute's Center to Reduce Cancer Health Disparities, Freeman wrote: "I began to see that cancer's invasiveness was deeply rooted in human conditions, and began asking questions such as: What does it mean to be black in America? What does it mean to be poor? And what does it mean to be black and poor and at the same time to have cancer?" (Freeman 2014: A27).

That African American women have the highest rate of mortality from breast cancer in the United States – a gap that emerged in the late 1980s and continues to widen – is, by all accounts, indicative of racism's synergistic effects combined with gender-based discrimination, the stress of living in poverty, and difficulty in obtaining timely, appropriate health care and other resources.[6] More difficult to explain through the emphasis on risk factors or even an awareness of barriers to health care is the finding that, among US women under 40, African American women have the highest incidence of breast cancer. Likewise, African American women are at much greater risk of being diagnosed with the "triple negative" subtype of breast cancer, which does not respond well to chemotherapy or the current forms of biological treatment.[7] From the standpoint of biomedicine, the prevailing explanations have pointed to variation at the level of oncogenes, cancer cells, and subtypes of breast cancer: a contemporary reading of race as biologically based.

By way of contrast, ecosocial perspectives in public health have advanced the argument that *all* biological phenomena, including diseases, are dynamic entities and not solely determined by a combination of genetic and behavioral factors (Krieger *et al.* 1997; Krieger, Chen, and Waterman 2011; Krieger 2013: 22, 23; see also Gilbert and Epel 2009; Piersma and van Gils 2010; Smith 2012). Consistent with the work of anthropologists on "local biologies," the aim of ecosocial perspectives has been to examine "embodied histories" as reflections of societal and ecological forces, cellular pathologies, and particular constellations of the life course.[8] Thus, for example, a critically important biomarker of breast cancer such as estrogen receptor (ER) status is no longer considered the "fixed trait of tumors," as the risk factors paradigm might suggest. Instead, it is understood to be a "flexible characteristic of cells" responding to shifts in hormonal levels and, equally importantly, to *nonhormonal* exposures.[9] As with health inequities generally, racial/ethnic disparities in breast cancer are

thus viewed as emergent and mutable: outcomes of socioeconomic and health-related policies, rather than "innate differences." The key, as Lewiston once noted, is in looking outward.

"Hot Spots": Place, Environment, and Breast Cancer

In the early 1990s, cancer activists articulated the need for "real prevention," by which they meant a departure from short-term trajectories of containment (through early diagnosis) and a concerted effort to resolve this health crisis for successive generations. Public debates on mammography, such as those aired at the 1994 San Francisco hearing, concerned ways of interpreting shifts in the patterns of disease over time; only secondarily did they address the value of a particular technology for population-based screening or the ascertainment of individual cases.[10] Equally important, activists began calling attention to a newly evident *geography of risk*: metropolitan areas and regions with well-documented and precipitous growth in the incidence of breast cancer, sometimes described as cancer clusters or "hot spots" (Anglin 1998; see also Farmer 2006 [1992]). At the same time, they posed questions about the environmental factors or other conditions that might account for those differences. Notions about personal responsibility for a cancer diagnosis were in this way dislodged by increasing public awareness that, as Judy Brady put it (1991: 27), "we are, in fact, victims of a social crime, the crime of poisoning our environment." As Sandra Steingraber explained from her dual position as cancer survivor and field biologist, to engage in such activities was no simple matter because it "mean[t] learning to get beyond the silence of reprieve in order to challenge the social and economic structures that allow cancer to lay claim to a third of us" (1991: 41, 39; see also 1997).

Thus, in the 1990s, the membership of One in Nine responded to state reports of increased breast cancer incidence on Long Island through their own community-based, participatory research on local cancer clusters; protests convened at the Nassau County courthouse; a public demand for research on environmental links to breast cancer (culminating in the multi-year, federally funded Long Island Breast Cancer Study Project); and the call for more extensive monitoring of pesticides and other contaminants within New York State.[11] Similarly, members of the Massachusetts Breast Cancer Coalition (MBCC), formed in 1991, called upon their state legislature "to declare breast cancer an epidemic" and to fund scientific research investigating the elevated rates of incidence documented for Cape Cod (MBCC 2014). Three years later, with financial support made available through the Massachusetts Department of Public Health, MBCC "founded 'a laboratory of their own' and named it Silent Spring Institute in tribute to Rachel Carson" (Silent Spring 2014b; see also MBCC 2014). In California, cancer activists worked with a state advocacy network (California Breast Cancer Organizations or CABCO), other constituent groups, and members of the state assembly on 1993 legislation to establish a statewide research institute – the California Breast Cancer Research Program, or CBCRP – with funding derived from a $.02 increase (per pack of cigarettes) to the state

tobacco tax, along with taxpayer contributions.[12] As has been the case for Silent Spring Institute, from its inception, CBCRP focused on developing a national model for collaborative and groundbreaking scientific research with practical application; "the identification and elimination of environmental causes of breast cancer" remains one of its priorities (California Breast Cancer Research Program 2014b; Milliken 2004; McPartland, Dantzker, and Portier 2015).

At the national level, WEDO and Greenpeace launched their 1994 campaign bringing together representatives from environmental justice organizations and "grassroots and national women's groups," along with "leading scientific experts," in a series of meetings whose ultimate goals were to influence US health policy as well as shape the recommendations ensuing from the UN's Fourth World Conference on Women (Women Health and Environment: Action for Cancer Prevention 1994, United Nations 1995).[13] One could make the case that another byproduct, eight years later, was the convening of an "International Summit on Breast Cancer and the Environment": the outcome of collaborative planning by environmental justice advocates, representatives from breast cancer organizations, and public health researchers from the University of California, Berkeley. Consensus findings from the International Summit, subsequently presented to a joint hearing of the California state legislature, included the call for innovative scientific research "that mirrors real-world exposures to environmental agents" and implementation of the precautionary principle in "public health/prevention" policies (Buffler 2002; Buffler *et al.* 2003; see also Joint Informational Hearing 2002; Milliken 2004).

In her ethnography of breast cancer organizations in the Bay Area of California, Maren Klawiter (2008) presented a quite different perspective on the role of science in "cultures of action." Bay Area organizations, in this rendering, largely eschewed scientific research – and especially that of cancer epidemiology – as delaying tactics and looked, instead, to political action as a strategy for reducing toxic exposures and thereby preventing breast cancer. An example of the latter was the annual "Toxic Tour of the Cancer Industry," whose purpose was to "stop cancer where it starts" (Klawiter 2008: 203, see also 204–211). Using the devices of street theatre, activists picketed the headquarters of companies that were alleged to produce carcinogens and/or profit from an ever-increasing market for cancer therapies. By way of contrast, the "institutional domains of public health and medicine," including the aforementioned International Summit on Breast Cancer and the Environment, were regarded as "colonizing new domains of risk" and legitimating biopolitical regimes (Klawiter 2008: 256–257).

Klawiter's account might be viewed as a presentation of "the politics of skepticism" regarding the limitations and cultural biases inherent to Western scientific methods, as well as the manipulation of technical expertise throughout the regulatory process, as Melissa Checker (2012) and other scholars of environmental justice have argued (see also Brulle and Pellow 2006; Brodkin 2009; Wilson 2010; Johnson and Ranco 2011; Cohen and Ottinger 2011). Thus, the widespread use of risk assessment methodologies to evaluate environmental hazards has been soundly criticized on a variety of grounds. Among the problems

noted are the potential for miscalculating the toxicities of specific chemicals, given the limits of testing to date; the tendency to underestimate both the means and levels of community exposures (dose); limitations in accounting for the synergistic and cumulative effects of repeated exposure to multiple chemicals; the under-rating of health effects due to the long latency period for many chronic diseases, including cancer; and the requirement of absolute proof of harm before remedial actions are undertaken (Checker 2007; Johnson and Ranco 2011; Rudel and Perovich 2012). In the 1995 "Cancer and the Environment" conference, risk assessment techniques were denounced as bureaucratic practices whereby "I decide how much poison you're going to get" (Anglin 1998: 195).

Furthermore, breast cancer activists have been vocal in their criticism of the early epidemiologic work investigating potential linkages between exposure to environmental contaminants and breast cancer. Studies by Nancy Krieger and colleagues at Kaiser (1994) and David Hunter and colleagues from Harvard (1997: 1253), for example, did not support the hypothesis of a link between "'environmental estrogens' such as organochlorines in pesticides and industrial chemicals" and increased breast cancer risk, as had previously been reported by Wolff *et al.* (1993). Their findings – along with the published responses of a segment of clinicians and researchers who took "reassurance" from them (Key and Reeves 1994: 1520; see also Anderson 1994; MacMahon 1994; Sternberg 1994; Taubes 1994) – were described by witnesses at the San Francisco hearing as evidence of a conservative trend in science (Anglin 1998: 193–196).

On a similar note, the membership of One in Nine and other activists who pressed for the Long Island Study Project (LIBCSP) found that institutional procedures for peer review effectively precluded "lay" involvement in the $31 million research program (1992–2002), and that decisions about study design or the chemical contaminants to be investigated were the province of researchers. The end result, according to Baralt and McCormick (2010: 1669), was that "advocates questioned whether the research methods and the variables selected by the scientists advanced the knowledge of possible carcinogeneity [*sic*] of environmental exposures," in particular, their decision to study a chemical that had long been outlawed in the United States. On the other hand, the investigators received criticism about the undue influence of the public over their work (McCormick *et al.* 2004). Yet, if this example of "community-initiated breast cancer and environment studies" did not fully adhere to the principles of participatory research, it nonetheless served as a landmark in the development of alternative approaches to the research process (Gammon *et al.* 2002; Brody, Tickner, and Rudel 2005; Winn 2005).

Thus, "science as usual" was disrupted by activist calls for "different science" and the promotion of models for the "democratization of science" (Anglin 1998; McCormick *et al.* 2004).[14] Perhaps the most radically inclusive orientation has been that taken by Silent Spring Institute, where community interests are treated as formally as the criteria of biological plausibility and (preliminary) scientific evidence in determining research priorities. "Including community

concern as a decision-making criterion helps avoid studies that, although elegantly designed, do not answer relevant questions," as Brody *et al.* (2005: 923) have observed. A further elaboration of this model is illustrated by the NIEHS-funded Northern California Household Exposure Study of 2006, through its efforts to combine "exposure assessment science" with the concerns of environmental justice and breast cancer advocacy (Brody *et al.* 2009). Congruent with the emphasis of NIEHS on community-based participatory research, the latter research team evaluated its own implementation of "community science" as a framework for investigating specific exposures to endocrine-disrupting compounds and other pollutants.[15]

That such approaches produce "good science" is attested by their records of publication on topics including the body burden of specific chemicals; reviews of the epidemiologic literature on environmental pollutants and breast cancer, with attention to methodologic problems and their potential resolution; new exposure biomarkers which could be implemented in breast cancer research; and the use of animal data to create "new directions for epidemiology, chemicals testing, and risk assessment for breast cancer prevention" (Rudel *et al.* 2007; see also Wolff *et al.* 2005; Brody *et al.* 2007; Zota *et al.* 2008; Rudel *et al.* 2014). In effect, they combine the insights of traditional approaches to breast cancer – namely, the emphasis on estrogenic exposures as increasing risk – with the multi-decade documentation of pesticides and other environmental contaminants as endocrine disruptors and, finally, the attention given by ecosocial perspectives to societal forces, ecological conditions, and the dynamism of local biologies over the life course.[16]

Then, again, "in mobilizing science for their own ends, grassroots groups have been creating alternative methods for knowing about and representing the health effects of pollution" (Cohen and Ottinger 2011: 8). While Cohen and Ottinger refer specifically to the US environmental justice movement, their argument extends to breast cancer organizations and cancer activists who have been strongly influenced – as has the American public, in general – by the transformative practices of that movement (Wilson 2010). Thus, in the midst of equivocation regarding the impact of environmental contaminants on human health, the Breast Cancer Fund produced its own version of "clear science": a series of monographs (2002–2010) summarizing "The State of the Evidence" about everyday exposures to radiation and chemicals and their potential connection to breast cancer (Breast Cancer Fund 2015a, 2015b). In her introduction to the 2010 edition, Janet Gray (2010: 10) characterized the report's primary objective as that of "provid[ing] the groundwork for economic and political changes that can lower the future incidence of breast cancer for our children and grandchildren" and noted that "we also join the collective effort to turn the tide on a number of other diseases."

Equally important, activists have brought their own life stories and specialized knowledge into scientific proceedings such as the International Summit on Breast Cancer and the Environment. Karen Holly's presentation, "as an 'at risk' African American female who was 34 years old when diagnosed with an aggressive stage III breast cancer," illustrated the complexities of embodied history

and, more than this, altered the terms of subsequent discussion.[17] Thus, she concluded with the following series of questions:

> So I ask you: if the air is polluted and the waters are tainted, if economics only allow me to afford to live in Richmond near chemical plants, and if my fruits and veggies are being sprayed and my beef and chicken are hormonally being enhanced, just what else can I do? What exposures, or combinations of exposures, must be looked at and studied? What are the studies being conducted to protect our future? Is poverty a carcinogen? (Holly 2002)

Holly well understood the synergies of race, class, gender, and cancer; the issue was whether scientists or policy makers would recognize or apply intersectional approaches in their approaches to environmental risk. In posing questions about "economics," she connected practices which target low-income communities of color as a "dumping ground" for toxic industry with the increased incidence of breast cancer among African American women under 40 (see also Pierce 2002). For those attending the International Summit, it was a powerful moment.

From a greater remove, perhaps the most noteworthy contributions of grassroots groups and advocacy organizations have been their articulation of the need for "real prevention" through the precautionary principle and continued support for publicly accountable, innovative science on environmental health. The precautionary principle shifts the focus away from the need for strong evidence of harm, in the form of adverse health effects, to the primacy of safety in regulatory procedures (Raffensperger and Tickner 1999). Kriebel *et al.* (2001: 871) summarize this logic as: "If a clearly safer alternative exists, why accept even a small, highly uncertain risk?"

In the context of breast cancer activism, "precautionary thinking" has meant the emphasis on health, as measured by the well-being of successive generations of women and their communities, and an expanded view of the research endeavor as a form of advocacy (Brody *et al.* 2005: 921). Thus, passage of the Breast Cancer and Environmental Research Act of 2008 – a bill that had previously been introduced, debated, and defeated over the course of nine years – is as much a testament to the doggedness of the grass roots and the partnerships formed with progressive scientists, as it is a reflection of the federal commitment to collaborative and groundbreaking environmental science (see also Platner *et al.* 2002; IBCERCC 2013). And it is in this context that we might place the findings from the President's Cancer Panel convened in 2008–2009, and the renewal of Rachel Carson's call for "our 'right to know.'"

NOTES

1 EPA (2007). Valerie Brown (2011: A485) makes note of the fact that TSCA has not been revised since its passage in 1976, "due in part to legislative gridlock and lack of consensus among stakeholders." At best, TSCA is viewed as an "ineffective and obsolescent" vehicle of regulation that has served to obstruct progress toward the creation and use of safer chemicals (Brown 2011: A485–A486; see also Scientific Understanding Work Group, The National Conversation on Public Health and Chemical Exposures 2011). Congressional efforts began in 2015 to modify or "reform" TSCA.

2 See McPartland, Dantzker, and Portier (2015) for their recommendations for developing a more "robust" chemical testing program at the EPA.

3 Leffall and Kripke (2010: vii, xi). The precautionary principle emphasizes "the assurance of safety" and preventative measures, where the threat exists for substantial harm and "even in the face of scientific uncertainty" (Goldstein 2001: 1358, Kriebel *et al.* 2001: 871; see also Cameron and Abouchar 1991; Raffensperger and Tickner 1999; Foster, Vecchia and Repacholi 2000; Grandjean 2004; Rabinowitz and Conti 2013). In summarizing results from the 2009–2011 *National Conversation on Public Health and Chemical Exposures*, Brown notes that a precautionary approach could include "a shift toward reintegrating environmental and occupational health with public health" (2011: a485; Leadership Council 2011).

4 On the relationship between HRT use and breast cancer incidence, see Clarke *et al.* (2006); Glass *et al.* (2007); Ravdin *et al.* (2007); Stewart *et al.* (2007).

5 Among other concerns, McKenzie and Jeffrys (2009: 57) observe that, "It is very common for studies to adjust for many factors simultaneously, which does not enable investigation of which specific factors could be important determinants of ethnic inequalities in survival." Furthermore, given the failure of cancer registries in the United States to routinely collect socioeconomic data, analyses of the relationship between social class and breast cancer incidence (or mortality) are, at best, speculative (see Krieger and Fee 1994; Krieger *et al.* 1999; Isaacs and Schroeder 2004; Anglin 2006; Clegg *et al.* 2009).

6 See ACS (2009, 2014). The negative impact on health has been variously described as the "weathering effect" (Geronimus 2001); "the Sojourner Truth Syndrome" (Mullings and Wali 2000; Mullings 2006); and the state of being "sick and tired of being sick and tired," as the civil rights activist Fannie Lou Hamer observed of her community and her own unsuccessful battle with breast cancer (DeMuth 1964).

7 Triple negative breast cancer is defined as a rare subtype of breast cancer that does not present or "express" receptors for estrogen, progesterone, or the epidermal growth factor, HER2/neu. See especially Carey *et al.* 2006 for their report on the Carolina Breast Cancer Study that examined racial differences in breast cancer subtypes and the higher prevalence of triple negative breast cancer among premenopausal African American women. While Tamimi, Colditz, and Hazra (2012) argue for a relationship between traditional risk factors and some molecular subtypes of breast cancer, it is with an important caveat. They note (2012: 159): "Identifying risk factors for less common subtypes such as luminal B, HER2-type and basal-like tumors [e.g., triple-negative breast cancers] has important implications for prevention of these more aggressive subtypes."

8 See Gaines (1992); Lindenbaum and Lock (1993); Lock (1995); Lock and Nguyen (2010).

9 See Krieger (2013: 23, 25); Carey *et al.* (2006).

10 At the San Francisco hearing, for example, Abzug noted that no specific evidence was provided for the contention that the secular trend of increased breast cancer incidence could be attributed to women's greater access to mammography screening in the United States (Chair's Remarks, Comment Period, Women, Health, and the Environment). See also Anglin (1998: 185–186, 197, note 3 on p. 204); Anglin unpublished field notes (1995).

It should be noted that there are other important dimensions of this critique of mammography – namely, that it relies on ionizing radiation, which is carcinogenic and to which breast tissue is especially sensitive; that it is an imprecise technology which produces both false negative and false positive laboratory results; and that far too many diagnoses have been made of precancerous conditions that would not

have developed into invasive breast cancer. See, for example, Fletcher's (2011) review of the impact of 35 years of mammography screening.

11 McQuiston (1992); One in Nine (2014); see also Gammon *et al.* (2002); Winn (2005); Osuch *et al.* (2012).

12 See the California Breast Cancer Research Program (2014a). See also the California Health and Safety Code Section 104145, and the California Revenue and Taxation Codes Section 30461-30462.1 and Section 18791-18796 (amended AB-28 Oct 11, 2007). In the most recent "Annual Report to the State of California Legislature," Kavanaugh-Lynch, Croughan, and Beckwith (2010) report that the California Breast Cancer Research Program (CBCRP) provided $16,872,114 for California-based research projects during 2010, and $215 million in grants since the inception of the program. Subsequent to 2010, reports from the CBCRP to the State of California Legislature are submitted every five years, rather than annually.

13 The San Francisco hearing was selected as the inaugural event, partly as the result of a report from the Northern California Cancer Center (1995) documenting the rate of breast cancer incidence in San Francisco Bay Area as the highest in the world.

14 For example, the National Institute of Environmental Health Sciences (NIEHS) and the National Cancer Institute (NCI) have jointly funded four Breast Cancer and Environmental Research Centers (BCERC) that have, as one of their aims, the fostering of partnerships between scientists and advocates in environmental health research. See Baralt and McCormick (2010), Wolff and Barlow (2011), and Osuch *et al.* (2012) for divergent views about the success of the BCERC as form of research collaboration and especially the impact of advocates' views on studies undertaken by the Centers.

15 See Brown *et al.* (2012); Adams *et al.* (2011). One of the issues the research collaborative addressed, ultimately with success, was the reluctance of one university institutional review board (IRB) to accept the full partnership of community organizations, especially regarding access to and use of study data (Brown *et al.* 2010).

16 As Birnbaum (2013: 321) has argued, human exposure to persistent organic pollutants may function like a kind of "uncontrolled medicine" disrupting the endocrine system and "resulting in a staggering increase in several diseases." Looking at specific periods of human development, or windows of exposure, helps to account for differences in body burden of persistent organic pollutants. Moreover, attention to the impact of particular chemicals on breast development, during these sensitive periods, may explain increased breast cancer risk. See also Wolff *et al.* (2005), Brody, Rudel, and Kavanaugh-Lynch (2011), and Pestana *et al.* (2013).

17 I am drawing here from Karen Holly's later testimony as part of "Breast Cancer and the Environment: Second Informational Hearing," a Joint Informational Hearing of the Senate Health and Services Committee and the Assembly Health Committee, San Francisco, October 23, 2002. This is identical to her presentation for the International Summit on Breast Cancer and the Environment.

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